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ORIGINAL ARTICLE

Primary Health Care Nurses' Experiences of treating Children with Atopic Eczema in Gauteng, South Africa

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ABSTRACT

Background: The prevalence of atopic eczema has increased in most African countries, including South Africa. Most patients with allergic conditions are seen by non-allergy trained healthcare workers, a situation that is also true for South Africa. The aim of this study was to explore and describe the experiences of primary health care (PHC) nurses in managing children with atopic eczema in a district of Gauteng.

Methods: A qualitative, explorative, descriptive, contextual design with phenomenology approach was used. The study population included nurses in PHC clinics in Gauteng who were selected by purposive sampling method. Data saturation determined the sample size, which occurred after three focus group discussions and four in-depth individual interviews. Data was analysed according to Tesch's steps of qualitative data analysis. Lincoln and Guba's model for trustworthiness and the ethical measures employed according to the Medical Research Council for South Africa.

Results: Three themes were identified: the effects of childhood atopic eczema; treatment challenges and recommendations. The second theme (treatment challenges) will be discussed in this article. In this theme, six categories were identified, namely: difficult assessment and diagnosis; drug management; low knowledge levels of PHC nurses; health education; ineffective referral system and limited treatment protocols.

Conclusion: This research highlighted many challenges experienced by PHC nurses in the management of childhood atopic eczema that may contribute to poor control of the disease in these children. Management guidelines were developed and are currently piloted. The results will be reported in future articles.

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INTRODUCTION

Atopic eczema is a common disease in many countries as shown by results from the International Study of Asthma and Allergies in Childhood (ISAAC) III study where prevalence in 56 countries were researched.¹ A systematic review of epidemiological studies indicated an increase in the prevalence of

atopic eczema in four of nine regions Africa, of which South Africa was one of the regions showing an increase.² This places a significant burden on health systems.¹ High numbers of patients with HIV and tuberculosis already burdens South Africa's health system. Other seemingly less important diseases, such as atopic eczema, have to compete for specific training of health care workers and funding to

purchase the necessary treatment.³ Furthermore, a worldwide study conducted by The World Allergy Organization Specialty and Training Council, found that the majority of allergic patients are treated by non-allergy-trained health workers.⁴ This situation is also true for South Africa.⁵ The South African health department is however committed to strengthening the effectiveness of the health system,⁶ to improve the quality of service; improve human resource planning, management and development; and to improve the availability of drugs in order to realise their vision which is: "A Long and Healthy Life for All South Africans".⁷

It has been widely researched that atopic eczema has a significant effect on the physical and emotional well-being of the patient and the family.⁸⁻¹² Atopic eczema is often undertreated, despite the disabling effect it has on the quality of life of the patient.^{8, 13} In a survey done in the United Kingdom (UK) for the National Eczema Society (NES), it became clear that parents of children with atopic eczema suffered due to too little information, treatment and support received from the primary health care clinician.¹⁴ A specialist dermatology nurse in the United Kingdom found in her practice that parents were frustrated during their first appointment with her, because they have not previously received the time for support and information from primary health care workers.¹² This article reports the findings of the first South African study done to explore and describe Primary Health Care (PHC) nurses' experiences regarding the management of children with atopic eczema in a district of Gauteng.

METHODOLOGY

A qualitative, explorative, descriptive and contextual research design with a phenomenological approach was used. The study was qualitative in nature as the purpose

was to gain a new and holistic understanding of the PHC management of children 0-12 years suffering from atopic eczema, in the public health care sector of a district of Gauteng. This phenomenon has not been researched before. Therefore, this was an explorative and descriptive study from 2013-2014. The study was contextual as it occurred in the PHC clinics in the public sector of a district of Gauteng. This district has 116 PHC clinics (excluding mobile clinics) but the exact number of PHC trained nurses was not available.¹⁵ Furthermore, this district is the largest city in South Africa with a population count of approximately 10.52 million people.¹⁶ Part of the population of this district consists of inhabitants of 180 informal settlements.¹⁷ In South Africa, as well as in Gauteng, 16% of the population have access to private medical care and 84% make use of the public health services, although many interchangeable use of medical healthcare also occurs.¹⁸ This clearly places a high burden on specifically the Gauteng public health sector.

In South Africa, the entrance point into the public health system is through the PHC clinics. Patients presenting at a PHC facility are seen by registered nurses (preferably a PHC nurse). The PHC nurses are responsible for the initial assessment and management of the patients, as well as identifying the need for referral to the medical doctor according to the Essential Drug List (EDL) or additional management by other members of the multidisciplinary team.¹⁹ If a condition (in this study, childhood atopic eczema) does not respond to treatment at the PHC level, or is complicated and needs more investigations or alternative treatment that is not available at the PHC level, the patient is referred to the next level of care. According to the referral system in South Africa, a patient should be referred from the PHC level to the secondary level and then if necessary to the tertiary level.

The study population were the PHC nurses employed in the provincial and local authority PHC clinics in a district of Gauteng. Purposive sampling was used to identify information-rich participants with lived experience of the phenomenon. The inclusion criterion for PHC nurses was that they must have treated (drug and/or non-drug) and/or referred children 0-12 years of age, suffering from atopic eczema to the paediatric dermatology outpatient department. The PHC nurses were purposively selected for in-depth individual interviews and focus group discussions. The parents at the paediatric dermatology outpatient department of the tertiary hospital were asked which clinic referred them to the outpatient department. After having identified the relevant clinics from the information received from the parents, the researcher contacted the operational managers of those clinics and explained the research to them telephonically and in person, in order to introduce herself and the research study and to obtain buy in to conduct the research at the clinic. If the operational manager gave permission for PHC nurses in that clinic to participate in the research, the operational manager and the researcher agreed upon a date and time for the individual or focus group interviews. On the arranged date and time, the researcher explained the research to the PHC nurses. Every PHC nurse who met the inclusion criterion and who agreed to participate in the research had to sign a document to give written consent to be interviewed and audiotaped. The researcher co-signed the document.

Phenomenological in-depth Individual interviews and focus group discussions were conducted with selected PHC nurses. The interviews were conducted in a quiet room in the clinics. The participants in the focus groups sat in a circle facing the researcher and skilled interviewer who formed part of the circle. In

the individual interviews, the participant and interviewer were seated next to each other, without any desks or other furniture forming a barrier between them. English is the official language to communicate in the public health sector and this was the language used during the interviews. The question asked during the interview was "How is it for you to treat children with atopic eczema?" Communication techniques were applied to confirm understanding of what the participants were saying. Interviews lasted between 45-60 minutes. Data was collected until data saturation occurred, that is, no new information emerged. A total of three focus group discussions and four individual interviews were conducted after which data saturation occurred. Field notes were kept during and directly after each interview.

The total number of participants were 18, of which four (4) participated in the individual interviews, six (6) in Focus Group 1, six (6) in Focus Group 2 and two (2) in Focus Group 3. Two participants is not the ideal size for a focus group²⁰ but the researcher decided to continue with the interview as these were the only two primary health care nurses in that clinic. The first step of data analysis was to transcribe all the interviews verbatim. The researcher and an independent coder both used Tesch's eight steps of the descriptive method of qualitative data analysis.²¹ Permission to conduct the study was obtained from the University of Johannesburg, Faculty of Health Science and the Gauteng Department of Health. Ethical principles according to the National Department of Health of South Africa namely autonomy, beneficence, non-maleficence and justice were adhered to.²²

Lincoln and Guba's measures of trustworthiness was followed.²³ Enhancement of credibility was achieved through prolonged engagement with the participants and data

analysis; triangulation of data collection tools – focus group discussions, in-depth individual interviews and field notes; member checking; as well as using a wide acknowledge method of data analysis. Transferability and dependability was achieved by providing a dense description of the research methodology and results, as well as provided direct quotes from the participants. Confirmability was enhanced, as an audit trail is available including the study proposal, raw data, as well as products of data reduction, analysis, reconstruction and synthesis.

RESULTS

Demographic characteristics of participants

The PHC nurses interviewed were 18 in total - four participated in the individual interviews and fourteen participated in the three focus group discussions. Focus groups 1 and 2 consisted of six participants each, while focus group 3 had two participants. Four of the PHC nurses worked in local authority PHC clinics and 14 in provincial PHC clinics. All the participants were female. The years of PHC experience ranged between nine (9) months and 21 years.

Childhood atopic eczema posed many management challenges for the PHC nurses, namely: assessment and diagnosis challenges; knowledge levels; drug management and limited treatment protocols; health education; as well as ineffective referral system.

Assessment and diagnosing challenges: PHC nurses had difficulty in diagnosing atopic eczema and were not always sure of the diagnosis. They expressed difficulty in differentiating between the different types of skin rashes.

"It is difficult, it is very difficult, because, sometimes you don't know the type of rashes, you don't know how to distinguish them, how to differentiate one from the other, so it is a very

difficult condition to manage the skin conditions." (Focus Group 2, Participant 4)

The PHC nurses also indicated that they needed time to effectively assess, diagnose and manage children with atopic eczema. They said that they did not always have the time because of the high number of patient in the PHC clinics.

"I think it is not a very simple condition to manage, because it takes time, especially in young age." (Focus Group 3, Participant 2)

"They grow with it, even if you can treat her now and then she'll come back again with the same problem." (Focus Group 3, Participant 1)

A PHC nurse stated that the children are often given repeats of previously prescribed treatment without thoroughly examining them, compounding the problem of effective assessment of the child with atopic eczema.

"The clinics only give treatment... they only give out repeats they don't examine the children. So the mothers prefers children to be examined, to be seen whether they are progressing or not." (Focus Group 1, Participant 6)

PHC nurses have inadequate knowledge of atopic eczema: PHC nurses often did not have enough knowledge on atopic eczema, the clinical presentation or the causes thereof. They often confused atopic eczema with other conditions such as fungal infections. If atopic eczema was diagnosed, the PHC nurses often did not know how to treat it and tend to rather refer the patients to the tertiary level of care. The PHC nurses often knew that certain applications to the skin could trigger eczema in children. They also knew that some children with eczema might have allergies.

"I don't think they are quite-quite clear about the skin. Not everybody is clear about the skin I must tell you." (In-depth interviewee 2)

"I think basically we need more information, I think the nursing practitioners needs more information on this topic." (Focus Group 3, Participant 1)

"We want to do it right, but you don't know what to do, how to do it. So that's why it is frustrating really" (In-depth interviewee 1).

"You find that sometimes it looks like fungal and also there is eczema" (Focus Group 2, Participant 5)

"We are not able to tell you anything. We don't even know what the cause is." (Focus Group 3, Participant 2)

"....even I as primary health care (nurse) we still struggle to treat these patients." (In-depth interviewee 3)

"It is eczema and I gave a referral letter." (In-depth interviewee 2)

".....some cases they are triggered by – uhm – allergies yes they are triggered by allergies" (Focus Group 3, Participant 1)

"Another thing is, you find that the mothers of these days, they are using these soaps like (product name) products, ehh – (product name) – of which the children they react immediately, because of their soft skin. So really it causes a problem and it is not easy to treat" (Focus Group 2, Participant 7)

Drug management and limited treatment protocols: The PHC nurses indicated that they had many challenges with drug management for children with atopic eczema. These challenges were categorised: no drug treatment available, or ineffective or insufficient quantities of treatment available as well as limited treatment protocols to guide the PHC nurses. The reasons for this were threefold. Firstly, some of the treatments that are shown to be effective for atopic eczema (that the children got from the tertiary hospital) did not form part of the EDL for the PHC level. Secondly, there were ordering issues, as most PHC nurses tend to give very

limited quantities of ointment to patients, influencing the maximum-minimum-stock-levels. Thirdly, the EDL, which is the standard treatment protocol that the PHC nurses follow, provides limited guidance on atopic eczema.

"The patients do not like clinics because they can see that once they go to the clinics their children won't be well and once they are coming to the hospital their children are becoming better" (Focus Group 2, Participant 2). (Field note: This refers to the fact that children are referred to the tertiary level and the drug treatment that they get there seem to be working better than what they receive at the clinics)

"And then when it comes to medication, most of the creams that they use at the hospitals, we don't have here in the clinic. What we have here for the topical treatment is what we have is aqueous cream that we advise them to bath with and to apply. We also have ehh – this for fungal – clotrimazole – that is what we have here. And also we have this ehh...what is this, they use it as soap... emulsifying ointment, that is what we have." (In-depth interviewee 1) (EDL indicates aqueous cream to be applied after bathing as a moisturizer.)

"Some do respond to this, to the advices, to the medicine, creams that we give them; some don't, then we refer them" (In-depth interviewee 1).

"We often don't have the medicines we need, uhmm – and when we do, you can only give a limited amount." (Focus Group 2, Participant 3)

Health education: PHC nurses mentioned that they give health education to the parents of children with atopic eczema. They also realized that health education forms a big part of the management of the child with atopic eczema. The health education provided was mainly on food avoidance, milk, clothes, hygiene, compliance to treatment and applications. However, the PHC nurses voiced that they were not always sure if the information that they gave the mothers was appropriate or correct. The PHC nurses also

were frustrated that sometimes the message given via media did not correlate with the health education that they gave.

"Health education is the most important thing" (Focus Group 3, Participant 2)

"We explain to them not to use this – what is it? – These strong soaps, Vaseline, whatever. We advise them to use the mild soap for the babies and to apply the aqueous cream the, the – what is it? – the ones without the perfume." (In-depth interviewee 3)

"...also that she must follow the instructions that I'm giving the mother isn't it?" (In-depth interviewee 4)

"Because sometimes you find the rash is in a vest form, so you see it has to do something with the type of clothing that the child was using." (Focus Group 2, Participant 5)

"And we also ask them about the milk formulas, because there are those children, who when they are taking milk products, you find that they are having eczema, but as soon as they are no longer taking the milk, they will outgrow it. Sometimes you ask them maybe if they can change maybe to the soya products or what" (Focus Group 1, Participant 4)

"And another thing, with those who are now on solids, we must also ask them about the type of foods they are giving, because like this ehh – preserved foods, you find that they, some of the children may react to those. So, you must try and tell them about cooking their own vegetables." (Focus Group 1, Participant 6)

"It's very difficult to explain so I think we need more explanations, even in our books it's only written that's how we are going to see the signs." She went further saying: *"Sometimes the EDL won't give you the answer that you can give to the mother when the mother wants to know. I think we need more information to give the parents."* (Focus Group 3, Participant 1)

"Even if you say to the mother it is not healthy to use, they don't listen to us, because the media comes first." (Focus Group 2, Participant 3)

Ineffective referral system: The findings indicated that the PHC nurses felt that the referral system from PHC clinics to the tertiary hospital and back seemed to be ineffective. There were four main reasons for this. Firstly, PHC nurses did not always know when to refer. Secondly, patient had to wait long to be seen by the dermatologists at the tertiary hospital. Thirdly, the lack of treatment or the ineffective treatment at the PHC clinics caused patients to stick to the tertiary level where the treatment they received seemed to be more effective than that of the PHC clinics. Lastly, there was limited communication between the different health care levels. One focus group indicated that they did not have problems with referring patients to the tertiary hospital, because they refer to the paediatric ward and not to the paediatric dermatology outpatient department.

"If you refer a patient from clinic level they always come back and they tell us they've been given appointments, but it's taking quite a long time for them to be seen and sometimes I just wonder as a primary health care nurse ... this is urgent for the patient and now they come back and we feel sorry for them, because we don't know what is the criteria for the patient to be referred" (In-depth interviewee 2)

"And it is very difficult to refer to uhmm - to a tertiary institution, because their dates are for months and months in advance." (Focus Group 2, Participant 1)

"...but now the down referral at the - at the moment, we don't have the proper treatment for them." (In-depth interviewee 1)

"We have no difficulties with referrals – yah. If we see the baby on her first visit if it is a severe eczema, we refer immediately to – to (hospital name) in ward (number). So they usually refer and book

them to see the dermatologist, they have their appointment with the dermatologist and they will go there for follow up treatment and they won't come back to us for any treatment and they will stay there until they are cured." (Focus Group 3, Participant 2)

"I also wish there could be communication between the doctors and the sister who is referring, because you'll find that I would be referring a patient, but, I will never know what was given to the patient." (Focus Group 2, Participant 5)

DISCUSSION

It is clear from the findings that the PHC nurses had many challenges in treating children with atopic eczema. Correctly diagnosing childhood atopic eczema is the first step in managing a child with this condition. One of the key elements for correct diagnosis is effective assessment of the child, which can be a time consuming activity. A South African study done in the same district as this research study, found that an overwhelming numbers of patients were seen at the PHC clinics and limited time was available for each consultation. This led to poor quality of health care and ineffective referral between nursing staff and doctors.²⁴ Communication is important to assess any patient. South Africa is a multi-cultural and diverse society with 11 official languages and many immigrants from neighbouring African countries speaking their own language and maybe a bit of one of the South African languages. Communication between the health care provider and patient is often part of the difficulties in effective assessment and management of illnesses, including childhood atopic eczema.^{25, 26}

A South African guideline for atopic dermatitis, focusing on medical practitioners, was published at the end of 2014 and the revised UK diagnostic criteria was recommended to be used for the South African

population.²⁷ The PHC nurse can also use this to diagnose atopic eczema. Furthermore, in assessing the severity of atopic eczema the PHC nurse can make an informed decision on what treatment level to start the child and/or when to refer the child to other members of the multi-disciplinary team.²⁸ The World Allergy Organization Specialty and Training Council found that the majority of allergic patients are not seen by allergy-trained health workers.²⁹ In a South African study, it was identified that health professionals (general practitioners and dieticians) had limited knowledge of appropriate diagnosis of allergies, dietary interventions and allergy prevention strategies. Most of these respondents believed they needed more education and training on the management of allergies.³⁰

The research presented in this article is the first South African study indicating the lack of knowledge of PHC nurses on childhood atopic eczema. Therefore, further research may be needed to assess the level of knowledge of PHC nurses on childhood atopic eczema using quantitative methods. Training should be conducted in order to improve the PHC nurses' knowledge on atopic eczema. There are different ways of addressing this. One way is to give childhood atopic eczema more attention in the nursing curriculum, specifically that of the Diploma: Clinical Nursing Science, Health Assessment, Treatment and Care.³¹ In-service training on childhood atopic eczema and the PHC management guideline for childhood atopic eczema should be conducted – this process has started.

As was the findings in another South African study done in primary health care settings in rural areas, factors that led to poor outcomes in chronically ill patients were identified. These factors were the lack of appropriate drugs; equipment; knowledge and/or clinical rigor of health care workers; money to return

for follow-up visits, which then led to defaulting the treatment; and a denial of patients on the seriousness of their chronic condition and the possible complications thereof.³² The challenges with enough and effective drug management for atopic eczema at the PHC level is still a challenge. The researcher is currently providing input towards the EDL and with the central pharmacy in order to increase the availability of emollients to the PHC clinics. There are many treatment guidelines and protocols for atopic eczema available worldwide, including for South Africa, but these mainly focus on medical doctors.²⁸ The treatment for atopic eczema, as set out in the EDL, which is the protocol for PHC nurses to use, is not fully aligned to the South African guideline for atopic eczema.^{19, 28} This partly explains why the PHC nurses have difficulty in treating the children with atopic eczema effectively.

There is consensus among allergy experts that educational interventions should form part of the management of atopic eczema.³³ However, the health education that health care professionals provide is often not evidence-based.³⁴ In a study where specifically trained nurses provided relevant health education to the patients or their parents, the overall outcome of the eczema, measured by well-known validated instruments, improved.³⁵ It is therefore important that PHC nurses be trained on the causes and triggers of childhood atopic eczema in order to give relevant health education. It is also imperative that the PHC nurses stay updated on the latest evidence-based health education that she provides as part of the management of the child with atopic eczema. The lack of knowledge of atopic eczema is one of the main reasons leading to unnecessary referral of infants with relatively mild atopic eczema to the secondary level of care.^{34, 35} The guideline on the management of atopic dermatitis in South Africa provides a

guide for referral to dermatologist services and this could be incorporated into a treatment protocol for childhood atopic eczema for PHC nurses.^{36, 37}

In a systematic review and meta-analysis done on psychological and educational interventions for atopic eczema in children, it was concluded that studies were not comparable, but there are indications that a multidisciplinary approach towards the management of childhood atopic eczema can improve the severity of the disease as well as the quality of life of the child and family.³⁸ Currently, there are no South African studies identified that specifically looked at the criteria for referral of a child with atopic eczema from the PHC level to the next level of care or to other members of the multidisciplinary team. The ill-functioning referral system in the district of Gauteng under study was one of the findings in another qualitative study.²⁴

The World Allergy Organization (WHO) states that a strong cooperative referral system between the different levels of health care is necessary for the optimal management of allergic patients. Furthermore, it is important to make an accurate diagnosis and be aware of the appropriate point at which to refer a patient to the next level of care.⁴ One of the five key issues identified to shape the future of allergy management in South Africa is to strengthen the links between primary and secondary level care facilities. Strengthening the referral system is one of the focal points in the 2015-2020 South African national strategic health plan.⁴⁰ In the Gauteng provincial health department, the district and sub-district teams are responsible for effective health care systems and they need to address the ineffective referral system. Up to now, this is still a challenge due to many factors influencing the number of patients in the public health care system.

Conclusion

It is clear that the PHC nurses in the public health sector of Gauteng experienced many challenges regarding the management of children with atopic eczema, with a lack of knowledge, including how to assess and diagnose atopic eczema in children and managing these children, including drug management, health education and referral as the bigger challenges. In order to address the management challenges, a PHC management guideline for childhood atopic eczema was developed through the AGREE II instrument.⁴¹ This guideline addresses the management challenges that were identified in this study and it is currently been implemented and the effect thereof evaluated. The findings from the implementation and evaluation of the primary health care management guidelines for childhood atopic eczema will be reported on in future articles.

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